Manual *of* Standards *for* Cancer Registration

These standards were developed via contract from the Middle East Cancer Consortium to the Rollins School of Public Health in the Department of Epidemiology of Emory University, Atlanta, Georgia, U.S.A.

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Third Edition, January 2002

First Edition was disseminated, reviewed, and revised at the Second Semi-Annual Meeting of the MECC Joint Cancer Registration Project Steering Committee, December 1998

Second Edition contained minor changes and was widely distributed among the MECC registries

This edition contains minor changes, but also allows for mass production and dissemination at the January 2002 MECC Steering Committee Meeting

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Brief History of the Middle East Cancer Consortium (MECC):

The Middle East Cancer Society started in Cairo, Egypt in 1994 as an idea among doctors, including Drs. Kahan, El-Bolkainy, Ibrahim, El-Najjar, and Polliack. Following meetings in Cairo, Bethesda, and Israel, when Dr. Klausner participated along with the Ministers of Health from Cyprus and Israel, the concept of the **Middle East Cancer Consortium** emerged.

The Main Aim of the MECC:

To increase knowledge and decrease incidence of cancer via the MECC's flagship, the Cancer Registry Project, by building standardized population-based cancer registries in the Middle East, with quality control, and eventually to be able to coordinate MECC activities, to compare data,
and to help make better public health decisions.

What is "Cancer"?

There are many elaborate definitions of "cancer". The easiest definition is that "cancer" is a group of diseases characterized by uncontrolled growth and spread of abnormal cells. If the spread is not controlled, it can result in death. For the purposes of defining reportable neoplasms, all tumors listed in the *International Classification of Diseases for Oncology, Third Edition* (*ICD-O-3*) with a behavior code (fifth digit) of 2 or 3 is considered to be a reportable neoplasm.

What is a "Cancer Registry"?

Cancer registries have been defined as organized systems for the collection, storage, analysis, and interpretation of data on persons with cancer, usually covering a hospital or group of hospitals. A population-based cancer registry collects the data from many hospitals and non-hospital sources in a defined geographic area and can serve to show ***incidence*** trends for cancer of different sites over time or between population subdivisions. With this information, incidence rates can be calculated. If the cases are then regularly followed, information on remission, exacerbation, prevalence, and survival can be obtained.

Registries are important public health tools:

- To verify and analyze the occurrence of cancer clusters
- To target public health programs (education, screening, etc.) in order to make the best use of limited public funds
- To compare acceptance rates and results of different cancer treatments (hospital, local, state, national, international)

What is a Diagnosis of Cancer?

The simplest way to state the answer is that a patient has cancer if a *recognized medical practitioner* says so. Then the question changes to "How can one tell from the medical record that the physician has stated a cancer diagnosis?" In most cases the patient's record clearly presents the diagnosis by use of specific terms which are synonymous with cancer. However, not always is the physician certain or the recorded language definitive. Rules concerning the usage of vague or inconclusive diagnostic language are as follows:

Using Ambiguous Terminology to Determine Reportability of Cancer

Consider as diagnostic of cancer	***NOT considered diagnostic of cancer without additional information****
apparent(ly)	cannot be ruled out
appears to	equivocal
comparable with	possible
compatible with/ consistent with	potentially malignant
favor(s)	questionable
malignant appearing	rule out
most likely	suggests
presumed	worrisome
probable	
suspect(ed)	
suspicious (for)	
typical of	

* Do not include patients who have a diagnosis consisting only of these terms. If a phrase such as "strongly suggestive" or "highly worrisome" is used, disregard the modifier ("-ly") and refer to the

guidelines above regarding the primary term.

How Changeable are the Diagnostic Items?

Most of the diagnostic information items are restricted to information available or procedures performed within the time limits defined for each item. However, with the passage of time the patient's medical record gets more complete in regard to information originally missing or uncertain. It is therefore established practice to accept the thinking and information about the case at the time of the most complete or detailed information. Thus, there may be changes in the coding of primary site, histology, extent of disease, residence, etc., over time as the information becomes more certain.

Sometimes, careful re-examination of medical records indicates that a case originally reported as cancer was not, in fact, a malignancy. This occurs most often if ambiguous terms are used or if the case was ascertained on the basis of a death certificate. Such cases must be deleted from the file and the sequence number of any remaining cases for the same person adjusted accordingly. On the other hand, if upon medical and/or pathological review of a previous condition the patient is deemed to have had cancer at an earlier date, then the earlier date is the date of diagnosis, i.e., the date of diagnosis is back-dated.

What is Cancer so far as Reporting to MECC is Concerned?

All cases with a behavior code of '2' or '3' in the *International Classification of Diseases for Oncology, Third Edition (ICD-O-3)* are reportable neoplasms. However, the following are optional:

- 8050-8082 Papillary and squamous cell carcinomas of the skin (C44.0-C44.9)
- 8090-8110 Basal cell carcinomas of the skin (C44.0-C44.9)
- Carcinoma in situ (any /2) and CIN III of the cervix (C53.0-C53.9).

Note 1: The above lesions <u>are</u> reportable for skin of the genital sites: vagina, clitoris, vulva, prepuce, penis, and scrotum (sites C52.9, C51.0-C51.9, C60.0, C60.9, C63.2).

Note 2: If a '0' or '1' behavior code term in *ICD-O-3* is verified as in situ, '2', or malignant, '3', by a pathologist, the case is reportable.

Note 3: Basal or squamous cell skin cancers should not be sequenced with other malignancies. *In situ*/CIN III lesions of the uterine cervix should not be sequenced with other malignancies. See 'Sequence of Tumor".

Reference Date: What Dates of Diagnoses are Included in MECC?

In general, the reference date for MECC is January 1, 1996. However, the reference date for Israel is January 1, 1960. For the registries in the Palestinian Authority and Cyprus, the reference date is January 1, 1998, and for Egypt (Tanta, Gharbia) the reference date is January 1, 1999.

Does Residency of the Patient Affect Reportability?

All cancers diagnosed and/or treated in persons who are residents of the reporting area at time of diagnosis are reportable. Further, any non-resident who is diagnosed and/or treated within the reporting area should be reported, but should be excluded from the calculation of incidence rates.

What is the Policy When There is More Than One Cancer?

The determination of how many primary cancers a patient has is, of course, a medical decision, but operational rules are needed in order to ensure consistency of reporting by all participants. Basic factors include the site of origin, the date of diagnosis, the histologic type, and the behavior of the neoplasm (i.e., *in situ* versus malignant).

In general, if there is a difference in the site where the cancer originates, it is fairly easy to determine whether it is a separate primary, regardless of dates of detection and differences in histology. Likewise, if there is a clear-cut difference in histology, other data such as site and time of detection are not essential. In some neoplasms, however, one must be careful since different histologic terms are used, for example, 'leukemic phase of' or 'converting to,' to describe progressive stages or phases of the same disease process.

How Are Multiple Primary Cancers Determined?

Rules recommended by the International Association of Cancer Registries will be used to determine the number of primary cancers reported within MECC. In general, only one cancer per primary site (utilizing the definition below) is reported over the lifetime of the patient. However, if a second primary of a different histologic group (utilizing the definition below) occurs either simultaneously or at a later date, a second primary in the same site should be reported.

Definitions:

1. ***Site differences***: Each primary site category (first three digits) as delineated in *ICD-O-3* is considered to be a separate site. The exception to this rule involves certain sites that were combined in the first edition of *ICD-O*. Between the first and second editions of *ICD-O*, some

subcategories having code numbers with the same first three characters in the first edition of *ICD-O* were split into separate three-character categories in *ICD-O-2 and -3,* and some subcategories having code numbers with different first three characters were grouped under the same first three characters. To avoid artifactual change in numbers of cancers by site over time subcategories should be defined as they were originally defined in *ICD-O-1*. *ICD-O-2 and 3* site codes considered to be the same "three-digit" grouping when determining multiple primaries are as follows: *(see next page)*

ICD-O-2 and -3 site codes considered to be the same "three-digit" grouping when determining multiple primaries

C01 Base of tongue
C02 Other and unspecified parts of tongue

C05 Palate
C06 Other and unspecified parts of mouth

C07 Parotid gland
C08 Other and unspecified major salivary glands

C09 Tonsil
C10 Oropharynx

C12 Pyriform sinus
C13 Hypopharynx

C19 Rectosigmoid junction
C20 Rectum

C23 Gallbladder
C24 Other and unspecified parts of biliary tract

C30 Nasal cavity and middle ear
C31 Accessory sinuses

C33 Trachea
C34 Bronchus and lung

C40 Bones, joints and articular cartilage of limbs
C41 Bones, joints and articular cartilage of other and unspecified sites

C60 Penis
C63 Other and unspecified male genital organs

C64 Kidney
C65 Renal pelvis
C66 Ureter
C68 Other and unspecified urinary organs

C74 Adrenal gland
C75 Other endocrine glands and related structures

2. ***Histologic group differences***: Differences in histologic group refer to differences between the 10 groups listed below which in turn are based on the first three digits of the *ICD-O-3* morphology code:

Histologic Group	***ICD-0* Morphology Code (first three digits)**
1. Epidermoid carcinomas	805-813
2. Adenocarcinomas	814, 816, 818-822, 825-850, 852-855, 857,894
3. Other specific carcinomas	803-804, 815, 817, 823, 824, 851, 856, 858-867
4. Unspecified carcinomas	801-802
5. Sarcomas and other soft tissue tumors	868-871, 880-892, 899, 904, 912-913, 915-934, 937, 954-958
6. Other specified types of cancer	872-879, 893, 895-898, 900-903, 905-911, 935, 936, 938-953, 972-974, 976
7. Lymphomas	959-971
8. Leukemias	980-994
9. Kaposi's sarcoma	914
10. Unspecified types of cancer	800

Note: Groups 4 and 10 are non-specific groups and cannot be satisfactorily distinguished from the other groups. If a cancer classified in either group 4 or 10 occurs either simultaneously or later than one in group 1-3, ignore the unspecified cancer.

Rules for Determining Multiple Primary Cancers:

1. A single lesion of one histologic type is considered a single primary, even if the lesion crosses site boundaries.

2. A single lesion composed of multiple histologic types is to be considered as a single primary.

3. If a new cancer of the same histology group as an earlier one is diagnosed in the same site, consider this to be the same primary cancer.

EXCEPTION 1: If an in situ tumor is followed by an invasive cancer in the same site more than two months apart, report as two primaries even if stated to be a recurrence. The invasive primary should be reported with the date of the *invasive* diagnosis.

4. Multiple lesions of the same histologic type

a. Simultaneous multiple lesions of the same histologic group within the same site (i.e., multifocal tumors) will be considered a single primary. Further, if one lesion has a behavior code of in situ and another a behavior code of malignant, still consider this to be a single primary whose behavior is malignant.

b. Multiple lesions of the same histologic group occurring in different primary sites are considered to be separate primaries unless stated to be metastatic.

5. Multiple lesions of different histologic groups

a. Multiple lesions of different histologic groups within a single site are to be considered separate primaries whether occurring simultaneously or at different times.

b. Multiple lesions of different histologic groups occurring in different sites are considered separate primaries whether occurring simultaneously or at different times.

DATA ITEMS

There are many data items that a cancer registry or cancer surveillance system can collect. The data items that follow are those that are agreed upon by MECC.

REQUIRED, CORE, or OPTIONAL

The term “Required” indicates that the data item is REQUIRED for submission to MECC

The term “Core” indicates that the data item is not required by MECC but is an essential CORE data item for cancer registry and cancer surveillance uses.

The term “Optional” indicates that the data item is not necessarily required by MECC, but is an OPTIONAL data item that may be of particular use or interest to a registry.

MECC REGISTRY IDENTIFICATION NUMBER — *Required*

Definition: A specific 2-digit code assigned to each MECC registry. The combination of this number plus the Registry Patient Number identifies a unique patient in the MECC data base.

Codes:

01 Cyprus
02 Egypt
03 Israel
04 Jordan
05 Palestinian Authority

Alternative:

01 Cyprus
02 Egypt (Gharbia)
03 Israel
04 Jordan
05 Palestinian Authority-Gaza
06 Palestinian Authority-West Bank

REGISTRY PATIENT NUMBER — *Required*

Definition:
The Registry Patient Number is issued by the registry to uniquely identify a person. All computer records pertaining to the same person must have an identical Registry Patient Number. This number may be assigned manually or by computer software.

The Registry Patient Number uniquely identifies a patient. The Registry Patient Number PLUS the Sequence Number uniquely identifies a reportable cancer.

SEQUENCE NUMBER (Lifetime Sequence) — *Required*

Definition:

Sequence number describes the chronology of diagnoses of all primary malignant and/or in situ cancers over the ENTIRE LIFETIME of the person, including the years before population-based cancer registration began.

If two or more independent primaries are diagnosed at the same time, the lowest sequence number will be assigned to the diagnosis with the worst prognosis. This means that extent of disease and morphology must be considered. If no difference in prognosis is evident, the decision must be arbitrary.

Note: Whenever a patient previously reported as having only one primary cancer is registered with a second primary, the sequence number of the first cancer should be changed from "00" to "01."

Basal cell carcinomas of the skin, squamous cell carcinomas of the skin, and in situ carcinomas of the uterine cervix are NOT sequenced as other in situ or malignant primary cancers. Only one basal cell carcinoma should be registered over the lifetime of the patient and should be assigned the sequence number of 97. Similarly, only once squamous cell carcinoma should be registered over the lifetime of the patient and should be assigned the sequence number of 98.

Benign tumors of the brain and CNS, if collected, are also NOT sequenced as other cancers.

Codes:

00 One primary only
01 First of two or more primaries
02 Second of two or more primaries
...
...
...
10 Tenth of two or more primaries
...
...
95 Benign tumor of the brain or nervous system (optional collection)
96 Carcinoma in situ of the uterine cervix (optional collection)
97 Basal cell carcinoma of the skin cancer (optional collection)
98 Squamous cell carcinoma of the skin cancer (optional collection)
99 Unspecified sequence number

PATIENT'S NAME — *Core*

Definition:
Document the name of the patient as provided in the source medical documents.

Country-specific Details:

Cyprus:

Patient's First Name (15 alphabetic characters)
Patient's Family Name (15 alphabetic characters)
Patient's Father's Name (15 alphabetic characters)

Current software utilized by the Cyprus Cancer Registry allows names to be recorded in Greek.

Egypt, Jordan, and Palestinian Authority:

Patient's First Name (12 alphabetic characters)
Patient's Last (Family) Name (12 alphabetic characters)
Patient's Father's Name (12 alphabetic characters)
Patient's Grandfather's Name (12 alphabetic characters)

For Female Patients:
Patient's Husband's Name (12 alphabetic characters)

Currently CanReg3 requires the names to be recorded in English rather than Arabic

Israel:

Patient's First Name (30 alphabetic characters)
Patient's Last Name (30 alphabetic characters)
First name of Mother (30 alphabetic characters)
First name of Father (30 alphabetic characters)

Current software utilized by the Israel Cancer Registry allows names to be recorded in Hebrew

PATIENT'S NATIONAL IDENTITY NUMBER — *Core*

Definition:
Document the unique National Identification Number of the patient.

Country-specific Details:

Cyprus: (7 numerical characters)
In Cyprus, the National Identity Number is assigned at the age of 12 and is six digits in length. For children under the age of 12, the mother's Identity Number plus a seventh digit indicating the order of birth of the child is used. The National Identity Number was initiated in 1960 following Independence.

Egypt: (14 numerical characters)

Israel: (9 numerical characters)

Jordan: (10 numerical characters)

Palestinian Authority:
(9 numerical characters; sometimes only 8-digits are recorded)
In the West Bank of the Palestinian Authority, the National Identity Number was initiated in 1967. All ID numbers issued between 1967 and 1989 begin with the number 9. All ID numbers issued between 1990 and 1994 begin with the number 8. All ID numbers issued from 1995 until the present start with the number 4.

AGE AT DIAGNOSIS — *Required*

Definition:

The age of the patient at diagnosis is measured in complete years of life, i.e., age at LAST birthday. For patients less than one year of age, code age as 000. For patients whose age is completely unknown, code age as 999. For patients aged 99, code age as 099.

If age is unknown/not stated, but year of birth and year of diagnosis are known, calculate age at diagnosis.

Codes:

(3 numeric characters)

000 Less than one year old
001 One year old, but less than two years
002 Two years old
...
... (actual age in years)
...
099 Ninety-nine years old
100 One hundred years old
...
...
120 One hundred twenty years old
...
...
999 Unknown age

DATE OF BIRTH — *Required*

Definition:

Indicate the date of birth of the patient. Date of birth is an 8-digit field. The first two digits indicate the day, the second two the month; the last four digits identify the year including century. Use only the DD/MM/YYYY (2-digit day/2-digit month/4-digit year) format. For example, the date of birth of a patient born on August 10, 1939 should be recorded as: 10/08/1939.

If date of birth is unknown, but age is known, estimate year of birth by subtracting the age from the current year, and code day as 99 and month as 99. If age is also unknown, code year as 9999.

Codes and Details:

DAY	(Two-digit day) 99 Unknown day
MONTH	01 January 02 February 03 March 04 April 05 May 06 June 07 July 08 August 09 September 10 October 11 November 12 December 99 Unknown month
YEAR	All four digits of year (including century) 9999 Unknown year

SEX — *Required*

Definition:
Document the sex of the patient from the source medical documents.

Codes:

1 Male
2 Female
3 Hermaphrodite* (optional)
9 Unknown

* A hermaphrodite is the result of a genetic anomaly that results in the presence of male and female sex organs on the same person. Although relatively rare (approximately 1 in 250,000 people), hermaphrodites are known to have different and unique cancer patterns and therefore are interesting to study.

MARITAL STATUS (at diagnosis) — *Optional*

Definition:
Collect and code the marital status of the patient **at the time of diagnosis**.

Persons of the opposite sex living together as part of a long-term personal relationship should be coded to “2" as married

Persons of the same sex living together as part of a long-term personal relationship should be coded according to their legal status (usually single, separated, divorced, or widowed.)

Codes:

1 Single - never married
2 Married
3 Separated
4 Divorced
5 Widowed
9 Unknown

PATIENT'S ADDRESS (at diagnosis) — *Core*

Definition:

Record the place where the patient was living when the diagnosis was made. For example, if a person is a resident or citizen of Saudi Arabia but is living and working in Jordan at the time of diagnosis, record the address in Jordan even though this person may not be considered a legal resident of Jordan. Residential status is recorded in the Residential Status field.

Country-specific details:

CYPRUS: Street name (15 alphanumeric characters - left justified)
House number (4 alphanumeric characters - left justified)
Zip Code (4 numeric characters)
City or Village (4 characters from a coded list)
Province (4 characters from a coded list)

EGYPT: Street name (30 alphanumeric characters - left justified)
House number (4 alphanumeric characters - left justified)
Zip Code (5 numeric characters)
City or Village (15 alphanumeric characters)
Governate (15 alphanumeric characters)

ISRAEL: Settlement or city code (4 characters) [Can be converted to district code]
Street name (30 alphanumeric characters)
House number (4 alphanumeric characters)

In Israel, the patient's address is copied in from the Population Registry after linkage through the patient identity number. A complete address history for the patient is maintained.

JORDAN: City name (12 alphabetic characters)
Village name (12 alphabetic characters)

PALESTINIAN AUTHORITY:
Street name (if present) and Village - (13 alphabetic characters - left justified)

In the West Bank there are no house numbers. Street name and village are recorded in English.

PATIENT'S TELEPHONE NUMBER (current) — *Optional*

Definition:
Collect and record the patient's most current telephone number. This may be useful for follow-up activities.

Country-specific Details:

16-digit numeric characters (left justify the digits)

CYPRUS: (8 numeric characters)

EGYPT: Not Collected

ISRAEL: Not collected/recorded

JORDAN: (9 numeric characters)

PALESTINIAN AUTHORITY:
Gaza: (9 numeric characters)
West Bank: (9 numeric characters)

RESIDENTIAL STATUS (current) — *Required*

Definition:
Document the residence of the patient from the source medical documents.

Country-specific Details:

CYPRUS: Legal residence of patient at the time of cancer diagnosis is based on "Residence Permission in Cyprus."

EGYPT: --- no information ---

ISRAEL: Legal residence is based on National Identity Number. If the patient has been issued an ID card, then he/she is an Israeli resident. Non-residents can be identified according to their passport number or some other document.

JORDAN: For Jordanians who live abroad, record their current place of residence in Jordan at the time of diagnosis. For Jordanians in Jordan, record their usual place of residence at the time of diagnosis.

PALESTINIAN AUTHORITY: --- no information ---

PLACE OF BIRTH — *Optional*

Definition:
Record the patient's place of birth from the source medical documents.

Country-specific Details:

CYPRUS: Place of birth for a Cypriot is the name of the city or village and if born abroad the name of the country. For foreigners the name of the country is recorded. Text is received and then coded.

EGYPT: The governate of birth is recorded. There are 27 governates coded 1-27.

ISRAEL: Country of birth, for those born abroad (coded list)
If born in Israel, --- no info ---

Note: For those born abroad, date of "Aliya" (immigration to Israel) is also collected.

JORDAN: Not Collected

PALESTINIAN AUTHORITY:
West Bank Born within the Palestinian Authority, code governate
Born outside Palestinian Authority, code country of birth using country codes
Name of the country and village is recorded in English

ORIGIN/ETHNICITY — *Optional*

Definition:
Record the origin and/or ethnicity of the patient from the source medical documents.

Country-specific codes:

CYPRUS: Cypriots
1 Greek
2 Turkish
3 Maronite
4 Armenian
5 Latin (Catholics)
Foreigners
6 Foreigner

EGYPT: Not Collected

ISRAEL: Not collected/recorded.
The country of birth is used to indicate a "race group" like Ashkenazi, etc. For Arabs, there is a certain code that indicates that s/he was born in Israel and is an Arab.

JORDAN: Not Collected

PALESTINIAN AUTHORITY: Not Collected

RELIGION — *Optional*

Definition:
Record the religion of the patient from the source medical documents.

For Cyprus and Egypt, the following codes are used:

0 No religion
1 Christian (includes Coptic, Greek Orthodox, Roman Orthodox, Protestant)
2 Jewish
3 Muslim
9 Unknown

For the Palestinian Authority, the following codes are used:

0 No religion
1 Christian (includes Coptic, Greek Orthodox, Roman Orthodox, Protestant)
2 Jewish
3 Muslim
8 Other (Samery, etc.)
9 Unknown

Israel and Jordan do not collect religion

SMOKING HISTORY — *Optional*

Definition:
Ideally only cigarette smoking should be recorded in this field, although cigar, pipe, and narghile smoking may be included inadvertently.

Codes:

0 Never smoked
1 Current smoker
2 Former smoker
9 Unknown smoking history

Note: Israel collects more detail than the above (not provided)

OCCUPATION — *Optional*

Definition:
Record in text format the occupation as reported in the medical record or on the death certificate. If the patient has had more than one occupation, ideally the longest held occupation should be recorded. For the purpose of cancer risk understanding, the registry is more interested in type of work rather than a stated profession. For example, if the patient states his profession to be a teacher but he has worked most of his life as a taxi driver, he should be recorded as a driver in public transportation.

Details:
This is a free-text data item. There are 25 alphabetic characters allotted. Recorded in English.

Cyprus and Israel have coded Occupation and Industry codes (3 digit codes).

DATE OF DIAGNOSIS — *Required*

The diagnosis date refers to the first diagnosis of this cancer by any *recognized medical practitioner*. This is often a clinical diagnosis and may not ever be confirmed histologically. Even if confirmed later, the diagnosis date refers to the date of the first clinical diagnosis and not to the date of confirmation. If medical and/or pathological review of a previous condition indicates that the patient had cancer at an earlier date, then the earlier date is the date of diagnosis, i.e., the date of diagnosis is back-dated.

Details:

DAY	Two-digit day 99 Unknown day
MONTH	01 January 02 February 03 March 04 April 05 May 06 June 07 July 08 August 09 September 10 October 11 November 12 December 99 Unknown month
YEAR	All four digits of year (including century) 9999 Unknown year

BASIS OF DIAGNOSIS — *Required*

Definition:

The basis of diagnosis indicates whether AT ANY TIME during the patient's medical history there was microscopic confirmation of the morphology of this cancer. It also indicates the nature of the best evidence available.

Details and Codes:

Non-microscopic

0 Death certificate only
1 Clinical only
2 Clinical investigation (including X-ray, ultrasound, etc.)
3 Exploratory surgery/autopsy
4 Specific biochemical and/or immunological tests

Microscopic

5 Cytology or hematology
6 Histology of metastasis
7 Histology of primary
8 Autopsy with concurrent or previous histology
9 Unknown

Notes:

Code 3: Includes diagnosis made at surgical exploration or by use of the various endoscopes (including colposcope, mediastinoscope, peritoneoscope). Use code 3 only if such visualization is not supplemented by positive histology or positive cytology reports or when gross autopsy findings are the only positive information.

Code 4: Clinical diagnosis of cancer based on certain laboratory tests or marker studies which are clinically diagnostic for cancer such as the presence of alpha-fetoprotein for liver cancer and an abnormal electrophoretic spike for multiple myeloma and Waldenstrom's macroglobulinemia. Although elevated PSA is non-diagnostic of cancer, if the physician uses the PSA as a basis for diagnosing prostate cancer with no other work-up, code Basis of Diagnosis as code 4.

Code 5: Cytologic diagnoses are based on microscopic examination of cells as contrasted with tissues and include smears from sputum, bronchial brushings, bronchial washings, tracheal washings, prostatic secretions, breast secretions, gastric fluid, spinal fluid, peritoneal fluid, pleural fluid, urinary sediment, and cervical and vaginal smears. Positive hematologic findings relative to leukemia, including peripheral blood smears are also included.

Codes 6 and 7: Histologic diagnoses are based on tissue specimens from biopsy, frozen section, surgery, or D and C, and bone marrow specimens (including aspiration biopsies).

For hematopoietic diagnoses such as acute lymphocytic leukemia, a diagnosis made by a bone marrow aspiration or a bone marrow biopsy is considered positive histology of the primary site (code 7).

LATERALITY — *Optional*

Definition:
Collect and record the side of origin of a cancer occurring in a pair site.

Codes:

0 Not a paired site
1 Right
2 Left
3 Only one side involved, right or left origin unspecified
4 Bilateral involvement, lateral origin unknown: stated to be a single primary
  Both ovaries involved simultaneously, single histology
  Bilateral retinoblastoma
  Bilateral Wilms' tumor
9 Paired site, but no information concerning laterality; midline tumor

Laterality codes of '1' - '9' must be used for the following sites except as noted. Only major *ICD-O-3* headings are listed. However, laterality should be coded for all anatomic subsites included in *ICD-O-3* unless specifically excluded. Such exclusions must be coded '0.'

C07.9	Parotid gland
C08.0	Submandibular gland
C08.1	Tonsillar fossa
C09.1	Tonsillar pillar
C09.8	Overlapping lesion of tonsil
C09.9	Tonsil, NOS
C30.0	Nasal cavity (excluding nasal cartilage, nasal septum
C30.1	Middle ear
C31.0	Maxillary sinus
C31.2	Frontal sinus
C34.0	Main bronchus (excluding carina)
C34.1-C34.9	Lung
C38.4	Pleura
C40.0	Long bones of upper limb, scapula and associated joints
C40.1	Short bones of upper limb and associated joints
C40.2	Long bones of lower limb and associated joints
C40.3	Short bones of lower limb and associated joints
C41.3	Rib, Clavicle (excluding sternum)
C41.4	Pelvic bones (excluding sacrum, coccyx, and symphysis pubis)
C44.1	Skin of eyelid
C44.2	Skin of external ear

C44.3	Skin of other and unspecified parts of face (if midline, use code ‘9')
C44.5	Skin of trunk (if midline, use code ‘9')
C44.6	Skin of upper limb and shoulder
C44.7	Skin of lower limb and hip
C47.1	Peripheral nerves and autonomic nervous system of upper limb and shoulder
C47.2	Peripheral nerves and autonomic nervous system of lower limb and hip
C49.1	Connective, subcutaneous, and other soft tissues of upper limb and shoulder
C49.2	Connective, subcutaneous, and other soft tissues of lower limb and hip
C50.0-C50.9	Breast
C56.9	Ovary
C57.0	Fallopian tube
C62.0-C62.9	Testis
C63.0	Epididymis
C63.1	Spermatic cord
C64.9	Kidney, NOS
C65.9	Renal pelvis
C66.9	Ureter
C69.0-C69.9	Eye
C74.0-C74.9	Adrenal gland
C75.4	Carotid body

Laterality may also be coded for sites other than those above, for example, “right colon” and “left colon”.

Definition:

Record in English the exact primary site of the cancer including laterality. Use standard abbreviations whenever available or possible. For example, if the primary site of the cancer is the "upper outer quadrant of the right breast", then record:

UOQ of R breast

Details:

25 alphabetic character field

Definition:

The Topography section of the *International Classification of Diseases for Oncology, Third Edition (ICD-O-3)* is used for coding the primary site of all reportable cancers. Site codes may be found in the Topography - Numeric Section of *ICD-O-3* or in the Alphabetic Index of *ICD-O-3* which includes both Topography and Morphology terms. Topography codes are indicated by a 'C' as part of the code. For all site codes in *ICD-O-3* ignore the decimal point when assigning the appropriate topography code.

The Introduction of *ICD-O-3* (page xxx) discusses the topic of "Site-Specific Morphology Terms." If the patient record has a site-specific morphologic term listed in *ICD-O-3*, use this topography code if no definite site is given or if only a metastatic site is given. For example, if the morphologic diagnosis is hepatoma with no other statement about the topography, code the primary site as 'C22.0' (liver), since this morphology is always indicative of a primary malignancy in the liver.

The primary site for any leukemia is coded to bone marrow ('C42.1'), since blood cells originate in the bone marrow.

Lymphomas originating in lymph nodes are coded to the appropriate lymph node chain, if known, or to lymph nodes, NOS. If an extranodal site is designated as the primary, code to this site. For example, a malignant lymphoma of the stomach is coded to primary site of stomach ('C16._'). If no primary site is stated, code to lymph nodes ('C77._'). If a lymph node is diagnosed in both a nodal and an extranodal site, and a determination cannot be made as to whether the lymphoma arose in the nodal or the extranodal site, code to the appropriate lymph nodes, NOS ('C77.9').

Kaposi's sarcoma should be coded to the primary site in which it arises. If Kaposi's sarcoma arises in skin and another site simultaneously, code to skin ('C44._'). If no primary site is stated, code to skin ('C44._').

Identify cases ONLY according to the primary site and NOT a metastatic site. If the site of origin cannot be determined exactly, it may be possible to use the NOS category of an organ system or the Ill-Defined Sites ('C76.0'- 'C76.8'). (See page xx of *ICD-O-3*). If the primary site is unknown or if the only information available pertains to a metastatic site, code the primary site as unknown ('C80.9').

Details and Codes:

Refer to, and use, *International Classification of Diseases for Oncology, Third Edition (ICD-O-3)*.

Definition:

Record the exact histologic type, behavior, and grade/differentiation/cell type of the cancer. Use standard abbreviations whenever available or possible. For example, a "poorly differentiated squamous cell carcinoma" can be recorded as:

PD SCC

Details:

25 alphanumeric characters

MORPHOLOGY CODES — *Required*

Definition:

The *International Classification of Diseases for Oncology, Third Edition (ICD-O-3)* is used for coding the morphology of all cancers. In the Alphabetic Index all morphology codes are indicated by an 'M-' preceding the code number. The 'M-' should not be coded. The '/' appearing between the histology and behavior codes is also not recorded.

To code morphology (histology, behavior and grade), use the best information from the entire pathology report (microscopic description, final diagnosis, comments). If the final diagnosis gives a specific histology, code it. Similarly, if grade is specified in the final diagnosis, code it. Exceptions are found on the following pages under "Histologic Type," "Behavior Code," and "Grade, Differentiation, or Cell Indicator."

Details and Codes:

Morphology is a 6-digit code consisting of three parts:

A Histologic type (4 digits)
B Behavior code (1 digit)
C Grading or differentiation or cell indicator (1 digit)

Refer to, and use, *International Classification of Diseases for Oncology, Third Edition (ICD-O-3)*.

HISTOLOGIC TYPE — *Required*

Definition:

When coding histologic type, usually the FINAL pathologic diagnosis is coded. All pathology reports for the primary under consideration should be used. Although the report from the most representative tissue is usually the best, sometimes all of the cancerous tissue may be removed at biopsy (excisional biopsy) and the report from the biopsy must be used. If a definitive statement of a more specific histologic type (higher code in *ICD-O-3*) is found in the microscopic description or in the comment, the more specific histologic diagnosis should be coded.

Details and Codes:

Histology should be coded using the following guidelines:

Single lesion - same behavior - two histologic terms mentioned

1. Code the histologic type using the following rules in sequence:

    A. When two terms are mentioned use a combination code, when appropriate, if one exists. For example, "predominantly lobular with a ductal component" should be coded to the combination code for lobular and ductal carcinoma (8522).
    B. When two terms are mentioned, use the more specific term if one is an 'NOS' term and the other term is more specific.
    C. When two terms are mentioned, use the code which best describes the majority of the tumor if A and B do not apply.

        Terms that indicate a majority of tumor:
        "predominantly"
        "...with features of..."
        "...major"
        "type"
        "with...differentiation"

        Terms that do **NOT** indicate a majority of tumor:
        "...with foci of..."
        "...focus of/focal..."
        "...areas of..."
        "...elements of..."
        "...component"

2. When two terms are mentioned and no combination code exists, code to the higher histology code in *ICD-O-3*.

Single lesion - different behaviors

Histologies with different behavior codes are coded to the histology associated with the malignant behavior.

Multiple lesions - considered a single primary

1. If one lesion is stated to be an 'NOS' term and the second lesion is an associated but more specific term, code to the more specific term.

2. For colon and rectum primaries:
   When an in situ or an invasive adenocarcinoma (8140) arises in the colon or rectum along with an adenocarcinoma in a polyp (8210,8261,8263), code as adenocarcinoma (8140).

   When a carcinoma (8010) arises in the colon or rectum along with a carcinoma in a polyp (8210), code as carcinoma (8010).

3. If the histologies of multiple lesions can be classified by a combination code, use that code.

Histology for non-microscopically confirmed cases

If a specific histology is stated for cases without microscopic confirmation, code the specific histology. It is possible to determine the specific histology of certain cancers by their radiographic appearance (astrocytomas), biochemical markers/laboratory tests (multiple myeloma), or visualization (Kaposi's sarcoma).

NEW HISTOLOGY CODES FOR LYMPHOMAS AND LEUKEMIAS

The following new terms, synonyms and codes have been added to the *International Classification of Diseases for Oncology, Third Edition*.

New Lymphoma Terms:

ICD-O-3 Code	Term
9673/3	Mantle cell lymphoma (*)
9688/36	T-cell rich B-cell lymphoma
9708/3	Subcutaneous panniculitic T-cell lymphoma
9710/3	Marginal zone lymphoma, NOS
9714/3	Anaplastic large cell lymphoma (ALCL), CD30+ (*)
9715/3	Mucosal-Associated Lymphoid Tissue (MALT) lymphoma
9716/3	Hepatosplenic (*) (gamma - delta) cell lymphoma
9717/3	Intestinal T-cell lymphoma
	Enteropathy associated T-cell lymphoma

New Leukemia Terms:

ICD-O-3 Code	Term
9821/3	Acute lymphoblastic leukemia, L1 type (*)
	Acute lymphocytic leukemia, L1 type (*)
	Acute lymphoid leukemia, L1 type (*)
	Acute lymphatic leukemia, L1 type (*)
	Lymphoblastic leukemia, L1 type (*)
	FAB L1 (*)
9826/3	FAB L. (*)
9828/3	Acute lymphoblastic leukemia, L2 type
	Acute lymphocytic leukemia, L2 type
	Acute lymphoid leukemia, L2 type
	Acute lymphatic leukemia, L2 type
	Lymphoblastic leukemia, L2 type
	FAB L2
9840/3	FAB M6 (*)
9861/3	Acute myeloid leukemia, NOS (*)
	Acute mesoblastic leukemia, NOS (*)
	Acute granulocytic leukemia, NOS (*)
	Acute myelogenous leukemia, NOS (*)
	Acute myelocytic leukemia, NOS (*)
9866/3	FAB M3 (*)
9867/3	Acute myelomonocytic leukemia, NOS (*)
	FAB M4 (*)
9871/3	Acute myelomonocytic leukemia with eosinophils
	FAB M4E

9872/3	Acute myeloid leukemia, minimal differentiation
	Acute mesoblastic leukemia, minimal differentiation
	Acute granulocytic leukemia, minimal differentiation
	Acute myelogenous leukemia, minimal differentiation
	Acute myelocytic leukemia, minimal differentiation
	FAB M0
9873/3	Acute myeloid leukemia without maturation
	Acute mesoblastic leukemia without maturation
	Acute granulocytic leukemia, without maturation
	Acute myelogenous leukemia, without maturation
	Acute myelocytic leukemia, without maturation
	FAB M1
9874/3	Acute myeloid leukemia with maturation
	Acute mesoblastic leukemia with maturation
	Acute granulocytic leukemia, with maturation
	Acute myelogenous leukemia, with maturation
	Acute myelocytic leukemia, with maturation
	FAB M2
9891/3	FAB M5 (*)
	FAB M5A (*)
	FAB M5B (*)
9910/3	Megakaryoblastic leukemia, NOS (C42.1)
	FAB M7

(*) new term(s) for an existing *ICD-O-3* code

Definition:

The usual behavior codes are listed in both the numeric and alphabetic indices of *ICD-O-3*, following the histology code. If a pathologist calls a cancer in situ ('2') or malignant ('3') when it is not listed as such in *ICD-O-3*, code the stated behavior. (See Table 1, pages xxvi and xxvii, in *ICD-O-3*.)

Do not use behavior codes '6' or '9.' If the only specimen was from a metastatic site, code the histologic type of the metastatic site and code a '3' for the behavior code. The primary site is assumed to have the same histologic type as the metastatic site.

Code the fact of invasion, no matter how limited. Even a pathological diagnosis qualified as "microinvasive" must be coded malignant, '3.'

Details and Codes:

2 Carcinoma in situ; intraepithelial; noninfiltrating; noninvasive
3 Malignant

Note: "In situ" is a concept based on histologic evidence. Therefore, clinical evidence alone cannot justify the use of this term.

Synonymous terms for in situ (behavior code '2') are:

Bowen's disease (not reportable for C44.0-C44.9)
Clark's level 1 for melanoma (limited to epithelium)
Confined to epithelium
Hutchinson's melanotic freckle, NOS (C44._)
intracystic, non-infiltrating
intraductal
intraepidermal, NOS
intraepithelial, NOS
involvement up to but not including the basement membrane
lentigo maligna (C44._)
lobular neoplasia (C50.0)
lobular, noninfiltrating (C50.0_)
noninfiltrating
noninvasive
no stromal invasion
papillary, noninfiltrating or intraductal
precancerous melanosis (C44._)
Queyrat's erythroplasia (C60._)
VAIN III (C52.9)
VIN III (C51._)
CIN III (C53._) (Reporting optional)

GRADE, DIFFERENTIATION, OR CELL INDICATOR — *Required*

Definition:

Code the grade or degree of differentiation as stated in the FINAL pathologic diagnosis. If the grade or degree of differentiation is not stated in the final pathologic diagnosis, code the grade or degree of differentiation as given in the microscopic description or comment.

If a diagnosis indicates two different grades or degrees of differentiation, code to the higher grade code (Rule 6, page xxvii or xlii in *ICD-O-3).* Always code the higher grade/differentiation code, even if it does not represent the majority of the lesion.

If a needle biopsy or incisional biopsy of a primary site has a differentiation given and the excision or resection does not, code the information from the needle/incisional biopsy.

If there is a difference between the grade given for a biopsy of the primary site and the grade given for the resected specimen, use the higher grade.

If there is no grade provided for the primary site, code as 9, even if a grade is given for a metastatic site.

Usually there will be no statement as to grade for in situ lesions. However, if a grade is stated, it should be coded.

The grading or differentiation - or for lymphomas and leukemias, the designation of T-cell, B-cell, null cell, or NK (Natural Killer) cell - is described in more detail on pages xxix, xxxv, and 23 of *ICD-O-3*.

Details and Codes:

1 Grade I; grade i; grade 1; well differentiated; differentiated, NOS
2 Grade II; grade ii; grade 2; moderately differentiated, moderately well differentiated; intermediate differentiation
3 Grade III; grade iii; grade 3; poorly differentiated; dedifferentiated
4 Grade IV; grade iv; grade 4; undifferentiated, anaplastic
5 T-cell; T-precursor
6 B-cell; Pre-B; B-Precursor
7 Null cell; non T-non B
8 NK cell (Natural Killer cell)
9 Cell type not determined, not stated

When there is variation in the usual terms for degree of differentiation, code to the higher grade as specified below:

Term	Grade	Code
Low grade	I-II	2
Medium grade; intermediate grade	II-III	3
High grade	III-IV	4
Partially well differentiated	I-II	2
Moderately undifferentiated	III	3
Relatively undifferentiated	III	3

Occasionally a grade is written as "2/3" or "2/4" meaning this is grade 2 of a 3-grade system or grade 2 of a 4-grade system, respectively. To code in a three grade system, refer to the terms "low grade", "medium grade" and " high grade," above. Do NOT code low, intermediate or high grade for lymphomas since this refers to the Working Formulation groupings as described on pages xxx-xxxi in *ICD-O-3*

Coding Grade for Breast Cases

When the terms low, intermediate, and high grade are used and the grading system is specified as (Scarff) Bloom-Richardson ("SBR" or "BR"), code [the sixth digit] as grade code 1, 2, and 3 respectively. This is an exception to the usual rule for all other grading systems that low, intermediate, and high are coded 2, 3, and 4 respectively. In the (Scarff) Bloom-Richardson system, if grades 1, 2, and 3 are specified, these should be coded 1, 2 and 3 respectively.

Use grade or differentiation information from the breast pathology report in the following order:

1. Terminology (differentiation: well, moderately, poorly, moderately-well, etc.; grade: I, II, III, etc.)
2. Histologic grade (grade I, grade II, grade III)
3. Bloom-Richardson scores (range 3-9, converted to grade) (see below)
4. Bloom-Richardson grade (low, intermediate, high)

The Bloom-Richardson grading scheme is a semi-quantitative grading method based on three morphologic features of *invasive no-special-type* breast cancers. The morphologic features are:

1) degree of tumor tubule formation
2) tumor mitotic activity
3) nuclear pleomorphism of tumor cells (nuclear grade)

To obtain the final Bloom-Richardson score, add score from tubule formation plus number of mitotic score, plus score from nuclear pleomorphism. Seven possible scores are condensed into three BR grades. The three grades then translate into well differentiated (BR low grade), moderately differentiated (BR intermediate grade), and poorly differentiated (BR high grade).

CONVERSION TABLE FOR BLOOM RICHARDSON (BR) SCORE AND GRADE

BR combined scores	Differentiation/BR Grade	Grade Code
3, 4, 5	Well-differentiated (BR low grade)	1
6, 7	Moderately differentiated (BR intermediate grade)	2
8, 9	Poorly differentiated (BR high grade)	3

Bloom-Richardson score may also be called modified Bloom-Richardson, Scarff-Bloom-Richardson, SBR Grading, BR grading, Elston-Ellis modification of Bloom-Richardson score, the Nottingham modification of Bloom Richardson score, Nottingham-Tenovus or Nottingham grade.

Note: For further details of the SBR scoring system, see Dalton, Leslie W et al. Histologic grading of breast carcinoma in *Cancer* 1994, Vol 73(11), page 2766, Table 2.

Coding Grade for Prostate Cases

Usually prostate cancers are graded using Gleason's score or pattern. Gleason's grading for prostate primaries is based on a 5-component system (5 histologic patterns). Prostatic cancer generally shows two main histologic patterns. The primary pattern - that is, the pattern occupying greater than 50% of the cancer - is usually indicated by the first number of the Gleason's grade and the secondary pattern is usually indicated by the second number. These two numbers are added together to create a pattern score, ranging from 2 to 10.

If the pathologist gives only one number and it is less than or equal to 5, assume that it describes a pattern. If only one number is given and it is greater than 5, assume that it is a score. If there are two numbers, assume that they refer to two patterns (the first number being the primary and the second number being the secondary) and sum them to obtain the score.

If expressed as a specific number out of a total of 10, the first number given is the score, e.g., Gleason's 3/10 would be a score of 3.

For prostate cancer, use the Gleason's codes as follows:

1. If Gleason's score (2-10) is given, code as follows:

Gleason's score	Grading
2,3,4	I Well differentiated
5,6,7	II Moderately differentiated
8,9,10	III Poorly differentiated

2. If Gleason's pattern (1-5) is given, code as follows:

Gleason's pattern	Grading
1,2	I Well differentiated
3	II Moderately differentiated
4,5	III Poorly differentiated

If not identified as Gleason's, assume a non-Gleason grade system and code appropriately. If both are given, code the non-Gleason grade.

Grading Astrocytomas

Astrocytomas are graded according to *ICD-O-3* rules in this field. The use of World Health Organization coding of aggressiveness is reserved for assignment of grade for staging. In the absence of other information on grade, code cases as follows:

Term	Grade
Anaplastic astrocytoma	4
Astrocytoma (low grade)	2
Glioblastoma multiforme	9
Pilocytic astrocytoma	9

Grading of Non-Histologically Proven Cases

Where there is no tissue diagnosis, it may still be possible to establish the grade of a tumor through Magnetic Resonance Imaging (MRI) or Positron Emission Tomography (PET). In particular, it is now possible to grade brain tumors by this method. Thus, if there is no tissue diagnosis, but there is a grade/differentiation available from an MRI or PET report, code grade based on those reports. If there is a tissue diagnosis, grade should be from the pathology report only.

Designation of T-Cell, B-cell, Null Cell, or NK Cell for Lymphomas and Leukemias

Code any statement of T-cell, B-cell, null cell, or NK cell involvement whether or not marker studies are documented in the patient record. (See page xxiii of *ICD-O-3*) Additional terms that should be coded are T-precursor, T-cell phenotype and gamma-delta T (code 5); B-precursor, B-cell phenotype and Pre-B (code 6); non T-non B and common cell (code 7).

For lymphomas and leukemias, information on T-Cell, B-cell, null cell, or NK cell has precedence over information on grading or differentiation.

SUMMARY STAGE AT DIAGNOSIS — *Required*

Definition:

The *SEER Summary Staging Manual - 2000 (SSSM2000)* published by the SEER Program of the United States National Cancer Institute should be used for determining summary stage. The SSSM2000 should be used on cases diagnosed on or after January 1, 2001. Ignore the subdivisions such as L1, L2, L3, L4, LX, R1, R2, R3, etc. when determining stage.

When determining Summary Stage, consider all clinical and pathologic information obtained within four months of the date of diagnosis of the cancer UNLESS such information represents progression of disease following diagnosis or through completion of surgery(ies) in first course of treatment, whichever is longer. Metastasis known to have developed after the diagnosis was established should be excluded.

The priority for using information is pathologic, operative, and clinical findings. Autopsy reports may be used in coding extent of disease, applying the same rules for inclusion and exclusion.

Details and Codes:

0	In situ
1	Localized (Stage I for Lymphomas)
2	Regional by direct extension
3	Regional by lymph nodes
4	Regional by both direct extension and lymph nodes
5	Regional, not otherwise specified (Stage II for Lymphomas)
7	Distant (Stage III or IV for Lymphomas)
9	Unknown, undetermined

Leukemias and multiple myelomas are considered systemic disease and should be coded to '7.'

Cancers of unknown site ('C80.9') should be coded to '9.'

Death Certificate Only cases should be coded to '9.'

Note: The diagnosis of malignant pleura effusion for a primary cancer of the lung ('C34._') is considered to be diagnostic of metastatic disease. Thus, if malignant pleural effusion is present, code summary stage as '7.'

Note: The U.S. National Cancer Institute SEER Extent Of Disease (EOD) codes are optional.

PLACE (HOSPITAL) OF DIAGNOSIS — *Core*

25 alphanumeric characters, left justify

Record the name of the hospital making the initial (first) diagnosis of the patient.

MEDICAL RECORD NUMBER — *Core*

12-digit alphanumeric medical record number
Left justify the field

HOSPITAL REFERRED FROM (Code) — *Core*

Record the code number of the hospital from which the patient was referred.
3 digit code in Cyprus, Egypt, Jordan, and Gaza
2 digit code in West Bank
--- no info--- from Israel

HOSPITAL REFERRED TO (Code) — *Core*

Record the code number of the hospital to which the patient was referred.
3 digit code in Cyprus, Egypt, Jordan, and Gaza
2 digit code in West Bank
--- no info--- from Israel

CONTACT PHYSICIAN — *Core*

Text field - 25 alphabetic characters
Record the name of the principal physician taking care of the patient.
This is useful for follow-up.

Definition of FIRST COURSE OF CANCER-DIRECTED THERAPY:
Collect and record the first course of cancer-directed therapy. The concept of cancer-directed (definitive treatment) is limited to procedures directed toward cancer tissues whether of the primary site or metastases. If a specific therapy normally **affects, controls, changes, removes, or destroys** cancer tissue, it is classified as definitive treatment even if it cannot be considered curative for a particular patient in view of the stage of disease, incompleteness of treatment, lack of apparent response, size of dose, operative mortality, or other criteria.

Cancer tissue means proliferating malignant cells or an area of active production of malignant cells such as adjacent tissues or distant sites. In some instances, malignant cells are found in tissues where they did not originate and where they do not reproduce, such as malignant cells found at thoracentesis or paracentesis. A procedure removing malignant cells but not treating a site of proliferation of such cells is NOT to be considered cancer therapy for the purpose of this program.

If a patient receives ONLY symptomatic or supportive therapy, this is NOT classified as cancer-directed therapy. Do not code procedures which are only diagnostic (incisional biopsies) or are supportive or palliative only, for example, surgical bypasses, administration of pharmaceutic agents which are anti-inflammatories (given only to prevent swelling).

The term palliative may be used in two senses: (a) as meaning non-curative and (b) as meaning the alleviation of symptoms. Thus, some treatments termed palliative fall within the definition of cancer-directed treatment and some treat the patient but not the cancer. For example, radiation therapy to bony metastases is considered cancer-directed treatment because in addition to alleviating pain, the radiation also kills cancer cells in the bone.

Definition of "First" Course of Cancer-Directed Therapy for all Malignancies <u>Except Leukemias</u>

If there is no documentation of a planned first course of treatment, first course of treatment includes all treatment received before disease progression or treatment failure. If it is undocumented whether there is disease progression/treatment failure and the treatment in question begins more than one year after diagnosis, assume that the treatment is not part of first course.

If a patient refuses all treatment modalities and does not change his/her mind within a reasonable time frame, or if the physician opts not to treat the patient, record that there was no treatment in the first course. If treatment is given for symptoms/disease progression after a period of watchful waiting, this treatment is NOT considered part of first course. For example, if a physician and patient choose a wait and watch approach to prostate cancer or chronic lymphocytic leukemia and the patient later becomes symptomatic, consider the symptoms to be an indication that the disease has progressed and that any treatment is not part of the first course. All modalities of treatment are included regardless of sequence or the degree of completion of any component method.

Definition of "First Course" of Cancer Directed Therapy <u>for Leukemias</u>

When precise information permits, the first course of definitive treatment is to be related to the first remission as follows:

If a remission, complete or partial, is achieved during the first course of therapy for the leukemic process, include:

1. All definitive therapy considered as remission-inducing for the first remission.
2. All definitive therapy considered as remission-maintaining for the first remission, i.e., maintenance chemotherapy or irradiation to the central nervous system.
3. Disregard all treatment administered to the patient after the relapse of the first remission.

If NO remission is attained during the first course of therapy, record all treatment that attempted to induce the remission. Disregard all treatment administered to the patient as a subsequent attempt to induce remission.

DATE FIRST COURSE OF CANCER-DIRECTED THERAPY BEGAN — *Optional*

Definition:

Date First Course of Cancer-Directed Therapy Began is an 8-digit field. The first two digits indicate the day, the second two the month; the last four digits identify the year including century.

Details and Codes:

Record the earliest date that any of the first course of cancer-directed therapy began regardless of modality. In some instances, the date of diagnosis and the date of first course of cancer-directed therapy will be the same. The first course of therapy usually takes place over a two to four month interval and is based on the stage of the disease at the time of diagnosis. When determining the date that the first course of therapy began, consider all treatment which is stated to be part of the planned first course of therapy, but Do NOT consider treatment which is given because of disease progression or because of failure of the first course of treatment.

DAY Two-digit day
99 Unknown day

MONTH
01 January
02 February
03 March
04 April
05 May
06 June
07 July
08 August
09 September
10 October
11 November
12 December
99 Unknown month

YEAR All four digits of year (including century)
9999 Unknown year

Definition:

Record the surgery performed on the cancer. Surgeries that modify, control, remove, or destroy cancer tissue are considered cancer-directed.

Details and Codes:

0 No cancer-directed surgery
1 Cancer-directed surgery
7 Patient refused
8 Recommended, unknown if received
9 Unknown

RADIOTHERAPY — *Optional*

Definition:

Record cancer-directed radiation therapy. This includes beam and implant. Do not record radiation therapy to the male breasts following female hormone administration to shrink the breasts.

Details and Codes:

0 No radiotherapy given
1 Radiotherapy
7 Patient refused
8 Recommended, unknown if received
9 Unknown

CHEMOTHERAPY — *Optional*

Definition:
Record chemotherapy given to the patient. This includes single agent and multi-agent chemotherapy regimens.

Details and Codes:

0 No chemotherapy
1 Chemotherapy (single agent or multiple agents)
7 Patient refused
8 Recommended, unknown if received
9 Unknown

HORMONAL THERAPY — *Optional*

Definition:

Record the administration of hormones to the patient. Be sure to record the Prednisone that is often given in combination with multi-agent chemotherapy. Also record hormone surgery such as orchiectomy for prostate cancer as hormone therapy.

Details and Codes:

0 No hormonal therapy
1 Hormonal therapy (include prednisone given in combination with chemotherapy, e.g. MOPP; also, include hormone surgery such as orchiectomy or oopherectomy)
7 Patient refused
8 Recommended, unknown if received
9 Unknown

IMMUNOTHERAPY [BIOLOGICAL RESPONSE MODIFIER (BRM)] — *Optional*

Definition:
Record the administration of cancer-directed immunotherapies and biological response modifiers (BRM). Most commonly, these include alpha interferon and bone marrow transplantation, but there are many others.

Details and Codes:

0 No immunotherapy (BRM)
1 Immunotherapy (BRM) given (includes bone marrow transplant)
7 Patient refused
8 Recommended, unknown if received
9 Unknown

OTHER TREATMENT — *Optional*

Definition:
Record the administration of other complementary or alternative cancer-directed treatments here.

Details and Codes:

0 No other treatment given
1 Other treatment given (such as laetrile, holistic healings, etc.)
7 Patient refused
8 Recommended, unknown if received
9 Unknown

DATE OF LAST CONTACT OR DEATH — *Optional*

Date of Last Contact or Death is an 8-digit field. The first two digits indicate the day, the second two the month; the last four digits identify the year including century.

DAY Two-digit day

99 Unknown day

MONTH
01 January
02 February
03 March
04 April
05 May
06 June
07 July
08 August
09 September
10 October
11 November
12 December
99 Unknown month

YEAR All four digits of year (including century)

9999 Unknown year

VITAL STATUS — *Optional*

Record if the patient is last known to be alive or dead.

Codes:

0 Alive
1 Dead

UNDERLYING CAUSE OF DEATH — *Optional*

Record the underlying cause of death from the source medical documents.

Codes:

0 Patient is still alive
1 Patient died of cancer
2 Patient died of non-cancer cause
9 Patient died, cause of death not known